

Parenting with Arthritis A Resource for Patients by Patients

You're contemplating a step into parenthood and also live with inflammatory arthritis? Start with this resource written by patients for patients with arthritis. We've learned through our own personal trials and tribulations and want to pay it forward. This resource has also been reviewed by a leading occupational therapist and researcher in parenting and rheumatic disease, <u>Dr. Catherine Backman</u>. The resource is organized in the following topics - click on the titles below and take the first step in getting informed!

Physical Care of Children

Are you wondering how to adapt various physical tasks so your arthritis doesn't affect your ability to parent your child(ren)? Learn about a variety of life hacks for handling some common parenting tasks, like picking up and holding your child, getting your child in and out of a car seat, bathing and more!

Dealing with Fatigue and Flares

Raising children is both exhilarating and exhausting – and then add in a systemic disease that causes flares, pain and fatigue. Learn some tips on how to manage your arthritis, fatigue, sleepless nights and how to ask for help.

Impact on Children

Arthritis can affect your parenting. What impact might it have on your children? Learn more about the positive and negative impacts on your child(ren).

Parenting Resources

This section contains a list of the trustworthy websites cited in the parenting section of this resource. To connect with other people living with chronic disease, request to join the Mamas Facing Forward group on Facebook. It is a group a group designed to help parents or those considering pregnancy while living with chronic illness.



Physical care of children

Based on your current abilities, arthritis may affect your ability to do many things in life including the physical care of your children. Trying to figure how to adapt tasks specifically to your limitations can be trying at times. Your occupational therapist is an excellent resource for finding aids and alternative ways to complete tasks. As people who live with arthritis and who also have children, we want to share some useful "life hacks", or tips, for parenting with arthritis.

Picking up and carrying babies/children

- Pick your baby up with your larger joints, resting your baby on the inner part of your forearm near your elbows. It may be easier to hold your baby if you insert one arm between their legs while supporting the rest of their body with the other arm.
- Bend your knees to help ensure not too much weight is on your lower back and the extremities of your arms.
- Consider using a sling, which is a piece of cloth that can be worn around the body to support your child. A sling distributes the weight of the baby/child to a number of joints including larger ones.

I've had three children along with rheumatoid arthritis. I had amazing good health while pregnant, flares after. With good health care, family help, and being proactive, these were fabulous moments in my life! I'm now a grandma! My saying "if there's a will, there's a way".

- Read <u>this article</u> for an excellent overview of the various baby-wearing gear. Some things to consider when purchasing baby-wearing gear are:
 - Test out or even borrow baby-wearing gear before purchasing to see which one works best for you and your child.
 - o Remember your child may have certain preferences too. Be sure that they are part of the testing process.
 - Make sure you can use the baby-wearing gear independently. You can never be sure
 if someone will be around to help you use it.



- Test out the baby-wearing gear for short periods of time then slowly extend the use.
- Be careful in purchasing any child carriers with buckles if your hands have limited dexterity and strength. It may be very difficult to get these open particularly when you're alone and don't assistance.
- Consider buying second hand baby-wearing gear in this case someone else has worn it in and the buckles may be easier to open. Be careful that the gear still meets current safety standards.
- Have your child climb up to you when you are sitting on a chair or bed. It may be easier to
 hold your child and then get up from the sitting position, rather than bending down and
 picking up your child. It is important to ensure you have the necessary joint stability and
 lower body strength.
- Encourage independence early. The sooner your children can get themselves into the car seat, feeding seat, stroller, etc., means less pressure on your joints. Children as young as a year can be extremely perceptive and can assist in making many things easier for you while building their own independence and self esteem at the same time, a win-win for all.





Car seats

You may have limited dexterity and strength in your hands making it difficult to get your child in and out of the car seat, or ensure the buckles are properly secured. Here are a few tips on how you can adapt this task:

- Personally test out car seats in the store. Try to find the one that can be most easily opened and puts the least amount of pressure on your joints.
- It may be easier to get your child in and out of their car seat if you insert one arm between their legs while supporting the rest of their body with the other arm. This uses your larger muscles and joints that may better handle their weight.
- There is a product on the market called the <u>Buckle Bopper</u> that may help you open a car seat. Look into it and see if it's right for you!
- God blessed me with 2 healthy sons. Even though my hands and wrists are badly deformed, I found my way to do everything for them. And most of hold them close and give them that unconditional love.

 In return, I received their unconditional love. They are now grown men and started their own families showing accepting and
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unconditional love to all.

- When your child gets a little older, encourage them to get into their seats and tie up their buckles independently. After they are done, check to ensure everything is properly placed and follows appropriate safety standards.
- Tie up the buckles at the **top** of the car seat first in order to secure your (often wiggling) child. This will make it easier to tie them in the bottom of the car seat.
- Loosen up the straps to make it easier to get the straps over your child's arms. Be careful to tighten them again to respect the appropriate safety standards.
- Recruit older children to help you in getting the baby or child in the car seat. Even if they
 can't get their sibling in the seat, they may be able to attach the buckles. After they are
 done, check to ensure everything is properly secured and respects safety standards.
- Use a large object, like a key or screwdriver, to open the car seat button. Of course, be careful to not hurt your child while pushing on the button!



Bathing infants and children

Bathing children can be difficult because of limited and strength in your hands, shoulders, knees and back. Here are a few tips on how you can adapt this task:

- For infants, consider bathing them in a special infant bath that you can purchase at most local department and baby equipment stores. You can bathe them on your table or counter to minimize any time leaning over a bath which can cause pain in the back and shoulders.
- The specialized infant or toddler baths typically contain non-skid material to minimize any movement or slipping by your child. If your baby or toddler moves around less, it will reduce any sudden movements and stress on your joints.
- For older babies who can sit up independently, consider bathing them in the kitchen sink. This minimizes any time leaning over a bath.
- Ask your partner, family or friends for help with bathing.
- If you bathe your child in the bathtub, consider using non-skid mats in the bathtub to minimize any possible slipping of your child. If your child moves around less, it will reduce any sudden movements and stress on your joints.
- Consider sitting in the tub with your child. Not only is this easier on the joints, it can become a great bonding time as well!

Dressing children

Trying to dress your child at any age can be challenging at the best of times. When your child is an infant, you will be responsible for bearing the full weight of their bodies and supporting their necks while getting their clothes on. It may become easier as they age but then they begin to move and wiggle around! Here are a few tips on how you can adapt this task:

• Consider purchasing clothing with zippers instead of snaps which can be more difficult to open if arthritis has affected your hands.



- Consider using Velcro shoes on your child as tying laces is more difficult with arthritis in the hands.
- When choosing clothing, carefully consider what is easier for you to put on your child, such as elastic waistbands and cotton clothing which provides more give/flexibility. Clothing with buttons may be difficult to put on your child particularly when they start wiggling and squirming!



- Encourage independence in your toddler or preschooler. If you have bought clothing that is easier for you to put on them, it is likely easier for them to put on too!
- Use your child's natural movements to assist in getting their clothing on.
- Have a favourite toy, even your smart phone to distract a wiggling toddler who doesn't want to lay still for a diaper change.
- Read this article for excellent tips on dressing your child without pain.

Purchasing baby equipment

There is a variety of equipment out there for new parents to consider purchasing, such as strollers, play yards, feeding seats and more. Here are a few tips on how you can make some smart purchases:

- Test everything out in advance don't leave the store until you're sure this is a piece of equipment you can use independently!
- When buying strollers, consider the weight of the stroller so you can get it in and out of the care independently. Also, consider how easy it is to open and close.
- Advise family carefully on purchases. Strongly encourage them to consult with you prior to purchasing anything or give them guidance on what brands and features you need.



Playing with children

Children are always playing and often there will be a tug on your sleeve asking if you will join them. Although you may have the energy and ability to play with them, there may be times

when this is more difficult. Think about asking your partner, grand-parent or friend to come over for some active play. They may appreciate the quality time they can spend with your child(ren) while also providing an outlet for your child's boundless energy!

Childproofing your home

It can feel like childproofing your home means that you also can't access the things you need and want. Similar to purchasing equipment, think carefully about what you're buying and test it out in advance. Make sure you still address the most pressing hazards in the house and ask your partner to 'un-do' any of the childproofing when you need to use it.

I thought parenting multiples (twins) under the age of 1 was challenging. It requires creativity and patience. In some ways, it has made being diagnosed with RA easier. I'm used to trying to get sleep when I can or figure out how to juggle competing needs. It has also allowed me to learn how to ask for help when I truly need it. Some days are good and some days are just really tough. I learn from the tough ones - how to be a better parent or a better patient and how to take care of myself. The good days allow me to feel grateful and appreciative and feel more connected.



Dealing with Fatigue and Flares

The fact is that raising children is exhausting at the best of times, let alone when you live with a systemic disease that causes flares where pain and fatigue worsens. Parenting is a marathon, not a race to the finish. Add to this nighttime when an infant, preschooler and even school age child can keep you up at night. Through this it's important to put yourself first and remember that if **you** aren't well then you will not be able to effectively care for your child(ren). Here are a few tips on how you can manage arthritis, fatigue and flares:

- Manage your disease first and foremost. Take it slow some days if you need to.
- Manage your energy levels. For example, if you're child has kept you up all night, it's OK to slow down the next day or even for several days afterward.
- Take into account that parenting takes a lot of energy. You may not be able to do all of the things you did before you became a parent.
- Every parent has heard this but it will be re-stated here. <u>Sleep when</u> <u>your baby sleeps.</u> Your house may

As my children get older, I find I am busier trying to keep on top of their lives. It is much more mentally draining but so worth it if you can stay connected. They do not care so much about a sink of dirty dishes but giving them your undivided attention will pay off tenfold. So, I have to rest when they are in school and be prepared to let certain things slide in order to be there for them.

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be a mess, you may still be in your pyjamas but that's OK. Take a nap.

- Life is full of trade-offs. Set priorities about what is important to you and dedicate your energy to these priorities. Get help with any household chores or other commitments.
- o It's OK to pay for help, such as a cleaning service, if you can.
- Find people to talk to your own support network, other parents with arthritis, other new parents...everyone understands how tiring and exhausting newborns and children can be. Reach out to support networks, such the <u>Mamas Facing Forward</u> <u>Facebook group</u>



• Recruit a neighbourhood "nanny's helper". Pre-teens often want to get babysitting experience and are eager to come over to help for a few hours to help. Think of friends with children in this age group or ask around.

We've come up with a variety of "life hacks" for dealing with some common problem areas for parents who also happen to live with arthritis.

Sleepless nights

- Take turns waking up with your child in the night. When dealing with numerous waking's in the night, ensure that each partner gets a longer stretch of sleep, if at all possible.
- It's OK to sleep with your child at night if that enables everyone to get a better night's sleep.
- Sleep when your baby is taking a nap during the day.
- Even if you are exhausted, never underestimate the benefits of a walk with your child.

Super moms do not exist so if you are feeling too fatigued or too sore to go to play centres, it's ok to stay home. There will be another day to go out when you feel up to it.

You must sleep in the day when naps occur. The laundry can wait.

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Asking for help

All parents – whether they live with a chronic disease or not - need help in raising their children. We rely on our partners, family, friends, neighbours, daycare workers, teachers, and many others. It really does take a village to raise a child. Here are some tips on how to ask for help:

- Find small tasks that you don't feel a personal attachment to and that could be done by someone else in a short period of time.
- If someone asks for ways they can help you, assign them one of the small tasks you've identified.



 Consider paying for help if that makes it any easier. Groceries can often be purchased online and delivered to your home. A cleaning service can come in periodically to clean your house. There may be a babysitter that can come to your house to watch your children for a few hours.



Impact on Children

There are both positive and negative aspects that your children may experience living with a parent with arthritis. Most importantly, remember that for your child, you are likely one of the most important people in their life. To them, you are perfect. Because you have arthritis, you may find that you engage in more specific activities with your child, including spending more quiet time with them playing, reading, doing puzzles, cooking, etc. They may also see you take a number of medications on a daily basis, receive intravenous infusions, spend a lot of time with healthcare providers and potentially even undergo hospitalizations and surgery. As a result, your children may gain a new appreciation to certain aspects of life, such as:

- The fact that people come in all shapes and sizes. Not everyone is fully able to do all
 - aspects of life but this doesn't mean that they are any less of a person.
- Your children may learn to be more empathetic (someone who can share another person's feelings, thoughts or attitudes) when they see you live with arthritis on a daily basis.
- Strength does not only come in the form of muscles.

Be honest with your children about how you feel. They understand more than some people realize and children love to help people they love.



Educating your child

You may also want to consider how to teach your child about arthritis. Keep to the facts and explain what arthritis is and how it affects you in day-to-day life (e.g. I get more tired than other people which means I need to take a nap. My feet don't look like everyone else's because arthritis is causing damage to the joints in my feet.) There may even be questions from your child's friends about your physical appearance if you have any noticeable joint damage. There are some books available to help your children understand arthritis and how it affects you. Read more about the books "Why does Mommy hurt?" and Ravyn's Doll.

Of course, your children may also learn that Mom or Dad can get sick and that they (and people in general) are not infallible. This can be scary and may mean a number of discussions with them to ease any stress they may be having. Counselling may also be appropriate.

Managing emotions

When you live with pain and fatigue on an ongoing basis, it is completely normal that it may affect your behaviour towards those closest to you, such as your partner and children. There may be times when your child(ren) pick up on your frustrations and pain. Here a few tips on how to handle this situation:

- Don't be afraid to speak openly to them about how you're feeling.
- As your child(ren) get older, they may be more than willing to become part of your network of support. Don't hesitate to ask them for help based on what they are able to do at their age(s) (e.g. taking groceries from the car to the house, going upstairs to fetch something).

You may be surprised that when they understand more, they may want to get involved in your care. This may be

My now almost 4-year-old has a compassion and understanding that many adults lack, she understands some people need to rest more because their bodies are fighting an invisible battle. She asks with curiosity rather than judgement. The struggles are well worth the rewards!

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particularly important in periods when you need more help, such as recovery from surgery or a hospitalization. Always communicate openly about how you are feeling and ask your child(ren)



about how they are dealing with the fact that you are living with a chronic disease. Being open and listening will make them feel more comfortable in sharing their concerns or fears with you. It is not easy for children to see their parent in pain and struggling. While you are the one living with arthritis, arthritis will forever be a part of who they are as well. This is not a negative thing, it simply is. They will likely become more empathetic adults who understand inner strength. Who knows, they may even choose a career in the field of healthcare. They will have watched you manage and live a successful life, overcoming huge obstacles. Remember, as their parent, you are the most powerful influence in their life.

I was diagnosed with RA when my daughter was 6 months old and my son 3 years old. So they both grew up with that as a "normal" part of our family life. On one visit to my Rheumatologist, my knee was very swollen and an aspiration and steroid injection was required. Rather than have my children wait outside the room, they were welcomed to "help" with the procedure. My 11-year-old son offered to insert the needle, a future doctor in our midst, but instead was asked to hold my knee securely to assist my doctor. My 8-year-old daughter was asked to hold my hand and comfort me. They performed their duties wonderfully. We were given instructions as to aftercare and when we returned home, my children sent me to bed with an ice pack and delivered snacks and drinks to me for the rest of the day. For many children, that would not have been a welcome experience but for my kids it was a teachable moment and it included them in my care. Over the past 16 years, on many occasions, they have come to my appointments with me and know about my treatments, medications, side effects, etc.



Parenting Resources

- From This Point Forward
- Mamas Facing Forward Facebook group
- Why does Mommy hurt? (book for children)
- Ravyn's Doll (book for children)
- Arthritis, Pregnancy, and the Path To Parenthood
- Arthritis Ireland: Parenting with Arthritis



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